

ORIGINAL ARTICLE

Rehabilitation interventions for cancer survivors: The influence of context

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Abstract

Background. Today more and more people survive cancer. Cancer survivors need help to recover both from the cancer and the treatment. Rehabilitative interventions have been set up to meet their needs. However, there are studies that report no major effects following careful, targeted intervention. Furthermore, it seems difficult to define whether an effect is caused by the intervention or whether it is due to contextual parameters such as human interactions, the organisation, the staff, the physical surroundings or the general atmosphere. The present study examines the influence of three contextual parameters in rehabilitation courses for cancer survivors in Denmark. **Methods.** The study was based on an ethnographic fieldwork with participant observation at nine week-long courses, on in-depth interviews and on written sources. Fieldwork is well-suited for studying interventions in context, such as social interactions between people and their physical, material and institutional surroundings. The analysis is based on Duranti's and Goodwin's theoretical approach to context. **Results.** The findings are categorised into three contextual parameters. **The setting**, including its aesthetic value, its physical surroundings and the scheduling of the courses. **The behavioural environment**, which comprised work commitment and the care provided by the staff. **The language environment** insofar as it facilitated a sense of community. **Discussion.** The results demonstrate the influence of contextual parameters not formalised in the intervention programme. Contexts affect the outcome of an intervention because they frame and inform the teaching, communication and various forms of social gathering. The study suggests that the effects of the intervention as measured by quantitative studies cannot be properly interpreted without taking into account the context within which the intervention is embedded.

Today more and more people survive cancer. But the physical, emotional and socio-cultural impact of cancer screening, investigation, diagnosis, treatment and related issues can be severe. It has been acknowledged that cancer survivors need help to recover both from cancer and from treatment. Patients need to adjust to life with the disease and to overcome the various side-effects and after-effects of treatment [1–10]. Supportive care and rehabilitative interventions have been set up for cancer survivors to meet these needs, though mostly in industrialised areas of the world [11–16]. Some intervention studies report no major effects following careful, targeted intervention [17–19]. One of several challenges in intervention research regards

how to measure and explain effects of the intervention provided [20–22]. It seems difficult to disentangle various aspects of an intervention and to define which components are responsible for which effects. The intervention becomes a black box, and this makes it difficult to determine whether an effect is caused by the intended intervention or whether it is due to contextual dimensions such as human interactions, the organisation of the intervention, the staff, the timing, the physical surroundings or the general atmosphere [23–26].

The aim of this paper is to draw attention to possible contextual dimensions that need to be taken into account when discussing, validating and

acting on conclusions from quantitative intervention studies.

Theoretical framework

Our paper adopts a conceptual framework proposed by Duranti and Goodwin [28]. They specify four parameters of context: 1. *Setting* – a social and spatial framework within which encounters are situated; 2. *The behavioural environment* – the use of patterns of behaviour for framing talk; 3. *Language as context* – the way talk invokes context and provides context for other talk; and 4. *The extra-situational context* or background knowledge. The term context comes from Latin *contexus*, which means ‘to join together’ or ‘to compose’ [28]. Context is an act of composition, making connections, of weaving together parts of language, behaviour and surroundings into meaningfulness [28]. Generally speaking, one can say that context provides resources for an appropriate interpretation of an event. It is something people *do* – i.e. they contextualise – in order to make sense of something and ‘give form to interpretations’. Thus, context is not to be seen as a fixed, outer reality. Analytically, context can be understood as a kind of frame that becomes created and recreated around an event [29]. This means that the effect of a specific intervention (the event being analysed), for example physical activity, a lecture or a group session, cannot be understood without reference to context. Context involves a fundamental juxtaposition of two entities; the event being analysed and a field of actions, actors and surroundings within which that event is embedded [28]. In intervention studies such as randomised clinical trials it is the intervention that receives the analytical attention, while contextual parameters are omitted from consideration [28:3–10].

Design and methodology

The present study examines cancer rehabilitation courses for cancer survivors at a cancer rehabilitation centre (Rehabilitation Centre Dallund (RcDallund)) on the Island of Funen, Denmark. In this paper we focus on interventions in context. The courses were conducted by a team consisting of a medical doctor, two nurses, a physiotherapist, a social worker, a psychologist and a number of off-site experts such as a dietician and a pastor. Only cancer survivors who had finished treatment and had a life expectancy of more than six months could be referred to the centre by the hospital or by their general practitioner. Generally the courses were free of charge. Each of the courses included 20 cancer survivors. Most participants were women (over 80%) who were diagnosed with breast cancer, whereas the few men participating were diagnosed primarily

with prostate cancer, colorectal cancer, lung cancer and haematological malignancies [27]. The courses were basically structured in the same ways. Differences in content were primarily related to gender, cancer diagnosis and age. A course could be titled ‘Women and breast cancer’, ‘Women and gynaecological cancer’, ‘Men and cancer’ or ‘Adolescents and cancer’. Whereas the first two courses mentioned directed the content at specific cancer diagnosis, the last two courses mentioned covered a variety of cancer survivorship perspectives. The courses consisted of lectures on topics such as cancer diseases, social, psychological, sexual and spiritual/religious matters, physical activities, patient group work about ‘life after cancer’, ‘starting work again’ and ‘sexuality and partnership’. The participants were expected to attend social and cultural events in the evenings such as a ‘sing-along evening’ and a closing banquet. Throughout the day and in the evening the participants joined in informal gatherings. At the end of the course each participant made a personal ‘action plan’ to support the ‘action points’ that he or she chose to focus on after returning to daily life. The interventions aimed at strengthening the participants’ understanding of their life situation and at encouraging enjoyment of life, hope and belief in the future. They were assumed to help cancer survivors to achieve the best possible levels of physical, mental and social functioning.

The results are primarily based on Tjørnhøj-Thomsen’s ethnographic fieldwork in 2002 and 2004 at the cancer rehabilitation centre. It formed the qualitative part of The Research in Cancer Rehabilitation Care (FOCARE (in Danish)) project, which evaluates the effect of the courses at RcDallund [27]. It included participant observation at nine week-long courses [30,31] from early morning to late evening, joining in on almost the same conditions as the participants, observation of approximately 180 participants, in-depth follow-up interviews with a random sample of the participants in their private homes (23 in total) three to six months after the courses. We also included the participants’ written evaluations, which they produced at the last day of the course (approximately 200) [32,33]. In the interviews the participants were first asked open-ended questions relating to their personal cancer story, and to how the course of the disease and treatment had impinged on their lives and social interaction. The interviewer then asked more specific questions relating to the rehabilitation course (e.g. why they had attended the course, how it measured up to their expectations, and in what ways the course made them change their every day lives and life style). Fieldwork is particularly well-suited to studying interventions in context, for instance social interaction between people and their physical, material and institutional surroundings.

These interactions are by their very nature emergent. They cannot be scheduled in a programme and they are difficult to measure. Participant observation may, therefore, contribute important data related to context not mentioned in interviews because the informants take them for granted, simply forget to talk about them or are not aware of them [31:94]. Hansen also did a brief period of fieldwork at RcDallund in 2004 (ten days in total) following the staff in their daily work. The overall purpose of the ethnographic studies was to gain insight in how the rehabilitation programme was carried out, what the staff and participants did and said, and how the participants experienced the rehabilitation programme. The analysis aimed at generating knowledge about common patterns and themes within this particular human experience.

Ethical considerations

The studies were approved by The Danish Data Protection Agency. Prior to the fieldwork, participants were informed about the studies orally and in writing.

Analysis

After the fieldwork we produced written transcriptions of the interviews and read through the material (tape-recorded interviews and extensive field notes). The analytical strategy was inductive. Recurrent topics were identified, compared and categorised and then grouped in more general themes. Subsequently findings were analysed using the concepts about context [28].

Results

In the following we present our findings within the contextual parameters.

Setting

RcDallund is housed in a restored mediaeval castle on Funen. It is surrounded by a large park with roses and rhododendrons close to a lake with white swans and songbirds. The architecture and aesthetics of the castle differed markedly from those the participants were accustomed to, whether it was the colourless wards and the underground radiotherapy units at the hospitals or their private homes in flats or houses. When the participants walked up the broad stairs to enter the hall, statements like these were common: 'This is enchanting. I had never thought I should experience this' or 'It is like a fairytale'. The setting made the participants feel special and cared for in

ways that contrasted starkly with their experiences in the health system. As one of the participants expressed it in an interview a month after her stay:

It [Dallund] is a solace for the soul Just to stay at a place so lovely. It was clean, beautiful, and there was a very special atmosphere.... Just the fact, that someone is taking care of you. That you are being cosseted, having good food and that you are together with equals.

The setting also inspired them to do things (walking, cycling) that they did not normally practice. Also the course team used the surroundings to encourage interactions between the participants. They stressed the importance of the participants 'using each other' and exchanging experiences with one another by engaging in such activities as taking a morning tour around the lake because: 'You can have such a good talk, when you are walking'.

Setting is also a temporal context. The temporal organisation of the course framed and situated the activities, interventions and experiences. The week's schedule indicated that nearly all activities had a specific amount of time dedicated to them. When the team presented the schedule, they emphasised that meals were served at fixed times and the classes started at the time stated: 'We expect you to participate in the full programme, because we consider the elements of the programme to be relevant for you', as one course leader announced. A minimum of time was left for participants' leisure, but the staff underlined that it was legitimate to 'ditch a class'. At the same time they emphasised that: 'This is *not* recreation, this is rehabilitation'. Several participants experienced tension between what they wanted to do and what they considered themselves obliged to do. As two participants put it:

When you receive an offer like this (the course), you cannot in all decency do otherwise.

I think that the course is terribly demanding. But the staff is so nice and I don't have the heart to tell them. They mean so well.

Even if staff told us to do things at our own pace, I somehow felt their disapproval when I walked to my own room in the middle of the doctor's lecture.

Rehabilitation at the centre implied that the participants were active, willing to learn, took responsibility and made an effort to get better. Although most of the participants were happy and grateful to be attending the course, many felt the programme to be demanding. For instance they criticised the intensity

of the programme in their evaluation as almost the only point of criticism. As one of the participants said: 'I had hoped just to relax, read a good book and be on my own and talk to the other participants' and another participant: 'This week plan is more demanding than going to work'. The course progressed in a particular way. The staff insisted that lectures about medical aspects of cancer had to be scheduled before lectures about psychological, sexology and existential aspects. Wednesday was considered to be the most critical and tear-stained day and the day on which some participants wanted to go home, even if that seldom happened. The staff thought it was necessary for the participants to 'hit rock bottom' before the rebuilding could begin. This rebuilding should take place Thursday and Friday through paying particular attention to the individual participant's body and future concerns. As one nurse said:

It is much harder for the participants to cope with the psychological and existential dimensions. By arranging this for Wednesday, we ensured that the participants had got to know each other. At that point, their questions about the disease and the side-effects have been responded to and participants feel safe together. They have build up a kind of community. [...] After the two first days the participants should preferably have 'hit rock bottom' in order to get in touch with their worries, fears, hopes, wishes and needs.

The behavioural environment

The participants' feelings of being special and cared for were related to the team's practices. The team emphasised a special human quality in their work and contrasted this with what was perceived as the more inhuman quality of the health system where they had worked before. One of the staff said that he left the health sector because he wanted to show 'that doctors have a human side'. Another way of demonstrating special care for the participants was through food and meals.

Meals were served in a blue dining-room. White cloths covered the four tables, flowers were in vases, colourful napkins and candles were placed to establish a nice and friendly environment in the dining situation. The food was arranged on dishes to match in colour and composition. Breakfast and lunch were served as a buffet and the two-course evening dinner was served at tables. The kitchen prepared food following the official recommendations of a healthy diet including at least 600 grams of vegetables per day, less than 30% of fat in the meals served, home-baked bread including a high amount of cereals, fish and light meat. Food and meals constituted a topic of focus for the lecturing and discussions in the group

of participants. From the introduction on Monday to the departure on Saturday the staff – and later on also participants – had plenty of conversations concerning the diet. The team often declared that a healthy diet is a very important component of rehabilitation: 'We are serving a preventive diet, as the chef told the participants when she introduced the diet. It was not difficult for the participants – especially the women – and for the staff to agree that dietary components included in the meals served contained preventive elements. One participant said: 'I am the person responsible. If I don't eat the right food and don't do my exercise, I won't get better.'

Generally the participants talked positively about the diet served, but there were participants (especially the men) who disliked this focus on healthy eating. One man said: 'I miss my butter and a good sauce made with cream. Vegetables are okay, but I am not a rabbit.'

Language as context

All courses were initiated with a round of presentations lasting a few hours following the arrivals of the participants. Participants introduced themselves and were encouraged to verbalise their expectations for the course. Often the participants concluded their introduction as this woman did:

I don't think I need to say anything else because you know how I feel. We've all been through the same. We really do understand each other.

Fellow participants would then look at the speaker, some would nod, others would be tearful and a few would pick up a handkerchief. Some would utter: 'We have something in common', 'we understand each other' or 'We are in the same boat'. These utterances were repeated many times during a course and involved small gestures such as the placing of a hand on a shoulder, the passing of a handkerchief, the giving of a hug. This mutuality paved the way for exchanging experiences and encouraging reflexivity, as illustrated by this quote:

Being together with all these wonderful women has helped me to understand that I need to take more care of myself. I have to tell my husband that I'm not the same as before, and that I'll never be the same happy-go-lucky girl again. I have to rely on what I think and know will be the best for myself, and not so much on what other people think or feel.

The women told each other stories about feeling different from others and of how these differences

could render social relationships uncomfortable and cumbersome. They also exchanged stories about the emotional pain associated with the bodily changes caused by cancer treatment. A hug or a word from a fellow participant could encourage the participant to continue with a physical activity although he/she was tired. A supportive talk could persuade a fellow participant to stay at RcDallund even if it was hard emotionally.

However for a few of the participants the continual talk with other participants about illness became a negative experience. One woman felt that the course had a powerful negative effect on her. She felt so miserable when she got home that she started seeing a psychologist. Such cases were rare, but it was often mentioned that witnessing other participants' stories was heavy stuff even if it also invoked a feeling of not being alone with the anxieties that came on the heels of cancer.

Discussion

The results demonstrate the influence of some of the contextual parameters not formalised in the intervention programme. The influence of context cannot be accessed through questionnaires but needs to be identified through participant observations and in-depth interviews. While the staff considered the participants exchange of talk as an important ingredient in the intervention, they could not at first know or predict how a supportive talk could be accomplished. However, in the course of their work at the centre they had also learned from the participants' interaction with the surroundings. In this way, as we have demonstrated, the setting as context becomes important when considering the effect of the intervention. The aesthetics of the castle, the physical surroundings, the behavioural environment and the temporal organisation of the courses provided a social, spatial and temporal context for the activities at the centre. The behavioural environment in terms of the staffs' work commitment, the care provided by the staff and the level of catering confirmed for most of the participants' their status as unique human beings. The language, the verbal and the bodily interaction (e.g. the exchanging of stories and hugs) between the participants had a prominent place in facilitating a feeling of community and provided a caring context for the interventions.

These results indicate that context can affect the outcome of an intervention because it frame and inform instruction, interpersonal communication and various forms of social gatherings. We suggest that the effects of the intervention as measured by quantitative studies cannot be properly interpreted, unless contextual dimensions within which the intervention is

embedded are taken into account. Rehabilitation must, then, be interpreted as a process relying not only on the predesigned intervention programme but also on imponderables related to contextual parameters. Quantitative studies of rehabilitation interventions could benefit scientifically from taking context into consideration. Results from RCTs, meta-analysis or descriptive studies on interventions cannot stand on their own. It may be possible at least to some extent to replicate the lectures and the programmed content of the rehabilitation interventions. But it is not possible to control – and replicate – the human interaction and the social processes that are at the core of the sense-making going on. As human interaction is both informed and mediated by context, it is impossible to understand rehabilitation or evaluate the effect of an intervention without paying attention to context. In this article we have suggested three parameters that could guide and promote this attention to context but we do not claim them to be exclusive.

Such attention may encourage researchers and health professionals to raise critical and constructive questions about the results presented in intervention studies. But it may also encourage new methodological thinking. Ethnographic fieldwork is particularly well-suited to disclosing the significance of contextual parameters. This speaks in favour of combining quantitative methods with qualitative methods in research on rehabilitative interventions to cancer survivors. In addition it is important to consider that research itself is always an intervention [31]. Research questions, whether based on a questionnaire or an interview guide, may introduce new topics and new categories of symptoms and/or side-effects that the participant in the intervention had not been aware of, verbalised or even felt before. Tjørnhøj-Thomsen made this observation when some of the participants asked her how they should answer or understand a specific question in the questionnaire or when some participants worried about all the possible side-effects listed in the questionnaire. In this way the research creates a context for how people think and speak of their illness and is an example of the fourth contextual parameter, the *extra-situational context*, noted by Goodwin & Duranti [28].

It is central, of course, that cancer rehabilitation has the desired effects. But instead of concentrating only on the interventions (the events) as self-contained isolated entities, we propose a future development in intervention studies that includes contextual parameters in order to strengthen the validity of the studies.

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